



# **TRUSTEES' ANNUAL REPORT 2004-2005**

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## TRUSTEES' ANNUAL REPORT

### Reference and Administrative Details

**Name:** XP Support Group

**Registration No:** 1075302

**Address:** 2, Strawberry Close, Prestwood,  
Great Missenden, Buckinghamshire,  
HP16 0SG

**Trustees:** The following persons served as Trustees  
during the year and subsequently:

Mrs Janis Hannant Chairman  
resigned 17 December 2004.

Mr Christopher Jardine Chairman  
appointed 19 March 2005.

Mr Stephen Webb FCMA Treasurer

Mrs Sandra Webb Secretary

Miss Alison Fraser

Ms Linda Partridge appointed 19 March 2005

**Bankers:** Lloyds TSB Bank Plc  
Great Missenden Branch  
60 High Street  
Great Missenden  
Bucks HP16 0AT

**Independent Examiner:** Mrs Susan Sexton, ACMA

**Legal Advisor :** Mrs Allison Cunningham, LLB, HCA

**Medical Advisors :** Dr Celia Moss DM, FRCP, MRCPCH  
Dr Sheru George MBChB, FRCP

**Scientific Advisor :** Professor Brian Diffey, PHD, DSc, FIPEM

**Fundraising Coordinator:** Miss Victoria Nelson-Parker

**Health and Safety Officer:** Melanie Hearn – resigned February 2004.

## **Structure, Governance, and Management**

The XP Support Group (XPSG) was established as a charity under a Declaration of Trust dated 27<sup>th</sup> March 1999 and is constituted as an unincorporated association.

There must be a minimum of three Trustees who are selected because of their ability by virtue of his or her personal or professional qualifications to make a contribution to the pursuit of the objects or the management of XPSG. Trustees are appointed for an indeterminate period. No outside body or person has the right to appoint a trustee.

Trustees are provided with training in accordance with their individual requirements. Basic knowledge of the condition Xeroderma Pigmentosum is provided via written and audio-visual material. This knowledge base is updated as appropriate by the Medical and Scientific Advisors.

All significant decisions are taken by the Trustees who normally meet three times a year. The day to day management of XPSG's activities is delegated to the Secretary working in conjunction with the Chairman.

## **Objectives and Activities**

### **The aims of the support group are:**

- To relieve the need of persons with Xeroderma Pigmentosum (XP) and UV-related conditions and their families;
- To advance the education of the public in Xeroderma Pigmentosum;
- To promote research into Xeroderma Pigmentosum.

### **In order to achieve these aims we undertake the following activities**

- Raise funds for the XP Research fund set up by the XP Society;
- Assist families to attend Camp Sundown (a night-time camp held in New York State, USA) or to attend "The Owl Patrol", our own UK night-time camp held in February;
- Give grants for UV protective products;
- Raise public awareness by means of an educational campaign.
- Produce a Newsletter three times a year
- Offer telephone, e-mail and face to face support as required

## Achievements and Performance

During this last financial year we have produced our first business plan to cover the next five years of development of the group. This document will be used to guide us over the coming years. Copies are available from XP Head Office or can be downloaded from our website.

The Support Group ran another very successful Owl Patrol Camp in February, with visitors from USA, Germany and France. 25 Children with parents enjoyed the facilities of St Katherine's, the theme of the weekend was The Wild, Wild West. The children and adults could take part in range of activities which include for the first time, lace making, Scaelatrix, and pottery painting. Our speakers were Koos Jaspers and Anja Raans from Erasmus Medical Centre in Rotterdam, who brought us up to date with their current research into XP and other related conditions. For the first time we arranged individual appointments with Dermatologists and we would like to thank Celia Moss from Birmingham Children's Hospital and Alex Anstey from Gwent NHS Trust. Also our thanks go to Sheru George from Amersham Dermatology Unit who joined us for the Question and Answers session. At the welcome party we announced our Friends of the Year. This is an annual award given to someone who is not a volunteer or beneficiary of the Support Group who has given outstanding service to the Group. Our winners were Karen Ayres who ran the London Marathon on our behalf and Cynthia Shelley. Our Volunteer of the Year was Ian Greenwood.



The XP Support Group was chosen by the High Wycombe branch of John Lewis as one of the community projects to be supported in their management challenge for 2004.

A team of 12 managers led by Alix Dunstone were given the task of organising a one day camp aimed at the 11-16 year olds (patients and siblings). 15 children from all over the UK including Northern Ireland attended the camp with their parents which was held on Saturday 12 June at St Katharine's, Parmoor. The day started with lunch at St Katherine's followed by a coach journey to London to see "Fame - the Musical" at the Aldwych Theatre. Families returned to St Katherine's for a buffet party with Disco and the evening finished off with fantastic firework display. We have sent out thanks to

John Lewis for providing us with a truly memorable day. This weekend was used as a pilot for our first teenage camp which will be run in August 2006.

The Support Group was nominated for A Queens Voluntary Award by member Cathy Coleman, the results will be announced on the anniversary of the Queens coronation on June 2<sup>nd</sup> 2005.

The Support Groups website has now been redesigned and we continue to get an increasing number of visitors. In the last year we received just under 3,000 visitors. Telephone calls have continued to decrease averaging about 5 calls a day. The majority come from the Press, but we have an increase in the number of e-mails received, over 700 in the last year.

Press Coverage included, Woman Magazine, Readers Digest, Sunday Express and Hello. In November 2004 a documentary about Kira, aged 5 who has Solar Utaeria was featured on Channel 5, she was also featured on Central News. Sandra and Alex Webb appeared on This Morning TV and Central News.

### **Financial Review**

The Group began the year with a balance of £18,685. Income during the year was £22,331. Notable contributions were received from the Buckinghamshire Foundation (£3,000), BBC Children in Need (£2,300), Toby Celtic Club fund raising event (£2,053), Karen Ayres from her run in the London Marathon (£1,562), and Liverpool's Radio City Foundation (£1,000).

Expenditure during the year was £30,370. The main event of the year was again the Owl Patrol camp, costing £10,651. The Support Group also sent two families to Camp Sundown in the USA (£4,439), and made a contribution of \$5,000 towards the XP Society's research fund.

The Group ended the year with a balance of £10,646.

### **Plans for Future Periods**

During the next financial year in addition to the Owl Patrol Camp, we plan to roll out a new Patient pack which should help a newly diagnosed family through the different stages, dealing with pre-school up to adult hood, giving information about benefits and allowances as well as the management of the condition. We also plan to have a school pack which can be used in the Personal Social Health Education element of the National Curriculum.

We shall place a bigger emphasis on the training of volunteers, to ensure that they give their best service to the families as well as continue to enjoy being a volunteer.

We shall also be planning the replacement of Sandra Webb who intends to step down as Secretary and Administrator by 2007. She will continue to be a Trustee, but wishes to spend more time with her family.

This year more than ever we need to concentrate on Fundraising as the reserves that we had last year have now been used. We look to you the membership to help us with achieving these plans.

## WHAT IS XERODERMA PIGMENTOSUM

**Xeroderma Pigmentosum (XP) is a rare genetic disorder that causes extreme sensitivity to the sun's ultraviolet rays. Unless patients with XP are protected from sunlight, their skin and eyes may be severely damaged. This damage may lead to cancers of the skin and eye. XP has been identified in people of every genetic group all over the world. There are about 100 cases in the UK, many of which are undiagnosed.**

### Causes

Ultraviolet light damages the DNA in cells and disrupts normal cell functioning. DNA (deoxyribonucleic acid) in our genes contains all coded information needed to direct cell functions.

Two factors combine to cause the abnormalities in XP. First, a person inherits traits from each parent which, when combined, lead to an unusual sensitivity to damaging effects of ultraviolet light. Second, exposure to the sun, which contains ultraviolet light, leads to changes in the skin and eyes.

Damaged DNA is mended by the DNA repair system. But the DNA repair systems of people with XP do not function properly. As a result, un-repaired DNA damage builds and causes cancerous cell changes or cell death.

### Symptoms

Many persons with XP get an unusually severe sunburn after a short sun exposure. The sunburn will last much longer than expected, perhaps for several weeks. This type of sunburn will usually occur during a child's first exposure, and it may be a clue to the diagnosis of XP. However, some people with XP will not get a sunburn more easily than others, and the disease will be undetected until unusual skin changes appear over time.

Most patients with XP develop freckles at an early age. Continued sun exposure will lead to further changes in the skin, including irregular dark spots, thin skin, excessive dryness, rough-surfaced growths and skin cancers. These skin changes will resemble those of elderly people who have spent many years in the sun. In people with XP, these changes caused by sun damage often begin in infancy and almost always before the age of 20.

The eyes of a person with XP are often painfully sensitive to the sun and may easily become irritated, bloodshot and clouded. Non cancerous and cancerous growths on the eyes may occur.

### Treatment

There is no cure for XP, but much can be done to prevent and treat some of the problems it causes:

- Protection from ultraviolet light, by a combination of physical and chemical means. These include sun avoidance, shade, clothing, hats, optical filtration and sunscreens.
- Frequent skin and eye examinations.
- Prompt removal of cancerous tissue.
- Neurological examination in some cases

Text extracted from "Understanding Xeroderma Pigmentosum" published by US Department of Health & Human Services



## **HOW YOU CAN HELP**

### **DONATIONS**

All donations gratefully received. We are eligible for Gift Aid so remember for every £1 you give we can reclaim 28p if you fill in the Gift Aid declaration form available from the Office. Donations can also be made on-line at [www.xpsupportgroup.org.uk](http://www.xpsupportgroup.org.uk)

### **FUNDRAISING**

Organise an event, such as a sponsored event, coffee morning

### **VOLUNTEERS**

As camp grows we are seeking more volunteers, application forms can be obtained from the Office.

### **SPREAD THE WORD**

Show this report to friends and colleagues